




Experience of home monitoring of children with complex CHD during the COVID-19 pandemic: lessons learnt

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Original Article

Cite this article: Gillender J, McCullough JEM, Browne R, Sinclair M, McCrossan B, and Casey F (2025) Experience of home monitoring of children with complex CHD during the COVID-19 pandemic: lessons learnt. *Cardiology in the Young* **35**: 235–241. doi: [10.1017/S1047951124026295](https://doi.org/10.1017/S1047951124026295)

Received: 19 December 2023
Revised: 9 June 2024
Accepted: 7 August 2024
First published online: 27 January 2025

Keywords:

Paediatric cardiology; remote consultation; congenital heart disease; telemedicine

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Abstract

Objective: The COVID-19 pandemic presented unique challenges to global healthcare. Face-to-face outpatient care was dramatically reduced. This study implemented a remote consultation service via a mobile app (Pexip) to monitor patients with major CHD. **Design:** Study design was quasi-experimental and prospective. **Setting:** Remote consultations were carried out at a tertiary paediatric cardiology centre in Northern Ireland. **Patients:** Children with major CHD aged 0–16years in Northern Ireland. **Intervention:** The intervention was a Pexip-enabled remote consultation. **Outcome measures:** Primary outcome measures included the number of attendances to hospital both initiated and avoided via remote consultation. Remote consultations were conducted by doctor and/or cardiac specialist nurse or by specialist nurse alone (52% vs. 48%). **Results:** In the study, 32 patients enrolled; three were non-responders and a further two excluded. There were 201 remote consultations delivered (mean = 7.4). There were 12 admissions to hospital resulting from the remote consultation; the commonest indication was abnormal oxygen saturations (42%). There were 38 hospital attendances avoided, predominantly related to infant feeding and medication advice (both 42%). **Conclusions:** A significant number of unnecessary hospital attendances were avoided ($n = 38$). Remote consultation technology proved a user-friendly and valuable adjunct to the provision of ongoing specialist patient care in challenging circumstances. There was a reduction in parental anxiety, and both parents and clinicians found this initiative beneficial to patient care. There was prompt identification of unwell children on remote consultations.

Introduction

COVID-19 brought about an unprecedented shift in healthcare provision and saw a heightened level of public fear of the novel virus. In the Royal Belfast Hospital for Sick Children, face-to-face outpatient consultations were severely curtailed by as much as 75% during COVID-19, and Emergency Department (ED) attendances were greatly reduced. From March to August 2019, attendances to Belfast Children's ED were 20,880 compared with 14,909 for the same period in 2020. The remainder of patients were reviewed via telephone appointments. The paediatric cardiology department experienced a shift in workload towards unscheduled telephone calls, from worried parents, received by the secretarial team and specialist nurses. By their nature these ad hoc consultations lacked structure and consistency.

CHD in Northern Ireland has a prevalence of approximately 12 per 1000 live birth.¹ The birth rate in Northern Ireland for the year 2020 was 21,441.² Based on these figures, Northern Ireland's incidence of all forms of CHD would have been estimated at approximately 257 babies in 2020. An extrapolation of this data would estimate prevalence of CHD in the paediatric cardiology service at just over 4000 children across Northern Ireland. According to data published in 2022 from the National Institute of Cardiovascular Outcomes Research, approximately 20–30% of babies born with CHD may be classified as severe or life threatening and may need surgery within this first year of life.³ These children, in particular, would ordinarily require frequent monitoring and clinical assessment.

Remote consultations were already established in children with complex CHD under the care of the paediatric cardiology service in Belfast. In 2005, Morgan et al. began the pioneering work of remote consultations for CHD children in Northern Ireland.⁴ At this time, the technology used Integrated Service Digital Network lines installed at the patients' home along with a fixed camera. This new technology was well received by families. However, limitations of the technology included the image quality and the delay incurred by requiring a physical installation of equipment within the home. Further work was carried out in 2008 by McCrossan et al. using broadband technology as opposed to Integrated Service Digital Network lines as a means of conducting remote consultations.⁵ This research demonstrated a cost-effective way of

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monitoring patients which lowered parental anxiety and was further researched by the group in 2012 with similar outcomes.⁶ The paediatric cardiology department in Belfast has a proven track record of researching remote consultation technology amongst CHD patients. This study builds upon this original research with the added benefit of technological improvements. Primarily, this research focuses on the ability to use mobile devices with superior image quality and resolution along with a free mobile application (app) called Pexip (www.pexip.com). This would ideally result in a more seamless delivery of remote consultation technology to our CHD patients compared with that available previously. Building upon this body of research, this study will examine remote consultations delivered using mobile devices and will not require any additional equipment to be purchased or installed by the family. In the face of a global pandemic, the department was able to expand its existing home monitoring patient population to include and target those patients requiring frequent monitoring of their CHD in infancy. These patients would have ordinarily been seen face-to-face; given this was not possible, remote consultations were not limited by the government restrictions at that time.

This study aims to assess the application of remote consultation technology to monitor patients with significant CHD and determine if it can safely provide ongoing support to these patients and their families.

The role of remote consultation in contemporary healthcare is rapidly evolving. With technological advances over the past 10–15 years, mobile devices can be used as a secure means of delivering a remote consultation. Paediatric cardiology centres across the world have now begun to introduce remote consultation using platforms such as Zoom and Pexip as a means to monitor patients since the advent of COVID-19.⁷

Materials and method

Patients

Patient recruitment was from 1 October 2020 to 31 March 2022. A total of 33 patients were identified and a total of 32 patients were recruited to the study. The majority of suitable patients (23/33; 70%) were identified during their inpatient journey. A further six patients (6/33; 18%) were identified at outpatient clinic. A further 2 patients (2/33; 6%) were recruited from district general hospitals, and a further 2 patients (2/33; 6%) were recruited from home. Parents were given written information regarding the study proposal. Once this information was reviewed and parental queries satisfied, written consent was obtained from the child's parent. Only one family declined to participate having received the study information.

The inclusion criteria were children aged 0–16 years with CHD. Children with severe subtype CHD as outlined by Hoffman and Kaplan in 2002 were included.⁸ The sampling strategy of the study was purposive as patients were identified based on the nature of their CHD. These children are likely to have acute presentations in the neonatal period or early infancy.⁸ Although there were two patients with single ventricle pathology, these patients were later excluded from final analysis. This was due to one of the patients remaining as a long-term inpatient and the other patient had significant socio-economic issues which precluded inclusion. Complex single ventricle CHD has the highest infant mortality of all CHD within the first year of life.⁹ The benefits of home monitoring with this group of patients have been well researched

and proven to reduce mortality.¹⁰ Minor CHD patients were excluded.

Patients were recruited either as inpatients, outpatients, or via district general paediatric units within Northern Ireland. Parents were provided with written information regarding the study protocol, prior to providing informed consent verbally and online. Instructions regarding use of the Pexip platform were provided either via in-person demonstration or by written instructions supplied by e-mail. A select number of patients were provided with weighing scales and/or home oxygen saturation monitors ([Appendix 1](#)).

The mean age at recruitment was 9.3 weeks (median = 23; IQR = 27). Further, 50% of the children within the study had a co-existing congenital syndrome/abnormality; the commonest being trisomy 21 (7/27, 26%). Of the 27 patients' mothers, 12 received an antenatal diagnosis of their baby's CHD (12/27, 44%); 10 of whom were delivered in a tertiary maternity hospital (10/12, 83%). Moreover, 13 mothers delivered their babies in a tertiary maternity hospital (48%); the remainder were spread across district general hospitals within Northern Ireland. The average time from patient enrolment to first remote consultation was 23.6 days.

Patients remained in the study cohort until at least their first surgical procedure/intervention; post-operative review was also complemented by remote consultations along with face-to-face review. A decision was made to discontinue remote consultation review in collaboration with the child's primary cardiologist.

Outcome measures

Primary outcome measures included attendances/admissions to hospital either initiated or avoided via remote consultation ([Figure 1](#)). Avoided attendances were adjudged to be instances whereby any issues discussed during the remote consultation which would usually require an attendance to hospital, were avoided. Secondary outcome measures included changes in parental anxiety levels. These were measured using the State-Trait Anxiety Inventory. The State-Trait Anxiety Inventory tool had been used to assess levels of parental anxiety before the first remote consultation and after the final remote consultation. Participating parents completed a self-evaluation measure of their well-being by filling out the State-Trait Anxiety Inventory.¹¹ Parental feedback was sought at regular intervals as outlined in [Figure 2](#). This feedback was obtained via a questionnaire and telephone/video call with the parents. Collation of feedback was carried out by the Ulster University research team.

The focus of this paper is mainly on the medical care impact of the home monitoring programme. The impact of the home monitoring programme on parental anxiety levels has been analysed in detail and is the subject of a second paper due to be submitted by one of the researchers.

Intervention

Pexip is a remote consultation interface which is used in a wide range of organisations across the world, including global health services, government agencies, and within the education sector.¹² As part of the service, Pexip provides a secure mobile application which is fully General Data Protection Regulation compliant. The mobile app is free to download and links the child's family to a secure one-on-one remote consultation with the clinician. The remote consultation is protected by a numeric passcode. This application was already in use within the paediatric cardiology department prior to this study.

The unique benefit of this modality is that it can be installed on a mobile device with remote consultations delivered through the



Figure 1. Parent and child engaging in remote consultation (RC).

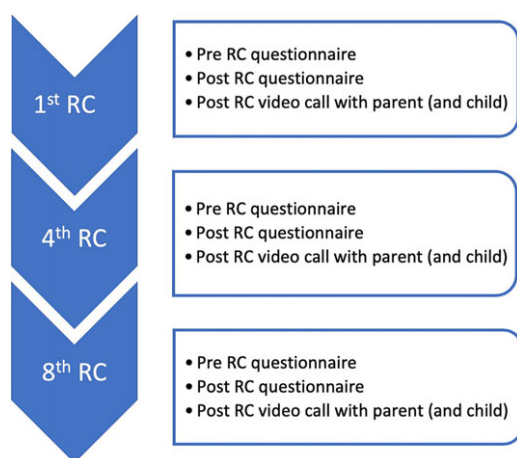


Figure 2. Parental feedback timeline. RC = remote consultation.

free Pexip mobile app. Furthermore, the app can use mobile data or wireless internet connectivity to make the call. This is in contrast to the previous setup within the department, using fixed camera installations.⁵

Members of the research team were able to demonstrate how to install and use the app prior to patient discharge from hospital. A simulated call was carried out with participants in order to enhance familiarity with the app technology and provide confidence to parents about its use. The team also developed a helpful step-by-step guide on how to re-install and use the app, should they require to.

Remote consultations

Remote consultations were performed either by a doctor, a paediatric cardiac nurse specialist, or by both simultaneously. The first remote consultation was arranged with the family, usually at the initial recruitment stage. The timing of subsequent remote consultations was based on the clinical needs of the patient as decided by the reviewing team and in conjunction with their primary cardiologist. Within the paediatric cardiology department, there was an established clinical nurse specialist service. All parents of children with major CHD have access to this service during working hours. Issues raised by parents through the clinical nurse

specialist service were able to be reviewed with an ad hoc remote consultation if this was deemed suitable.

The remote consultation involved a two-way audiovisual interface in which the parent and clinician can interact with each other and the child can be seen and reviewed in real time. Visual observations were recorded including the child's general demeanour, physical appearance, and colour; respiratory rate and work of breathing along with any surgical wounds were inspected. This information was recorded on a clinical pro forma at each remote consultation. Other clinical parameters such as weight, heart rate, and oxygen saturations were also recorded where applicable. The clinician and parent would discuss the child's current progress, and this was also recorded. Where applicable, close inspection of surgical wound was facilitated during the remote consultation. A clinical pro forma was designed and completed at each remote consultation.

Results

Primary outcome measures

A variety of CHD diagnoses were reported amongst recruited patients; the specific nature of these conditions is outlined in Table 1.

Of the 32 patients consented from the outset, three did not complete their initial remote consultation with a further two patients excluded from final analysis. The main reasons for non-response included one patient who was discharged home several months after recruitment when the clinical situation was stable (prolonged inpatient stay involving surgical procedure); one parent had difficulty installing/using technology; one family were unable to engage in service due to device compatibility issues, and they were also attending regularly for face-to-face reviews.

Of the remaining 29 patients, two patients with single ventricle anatomy, who would normally have been a priority for home monitoring, had to be excluded. Also, one of the children remained indefinitely as an inpatient having been referred for cardiac transplant; the other child had socio-economic circumstances which made the proposed use of remote consultations unsuitable for them.

The remaining 27 participants completed 201 remote consultations between them, mean 7.4 per patient (IQR = 4.75). During the entire study period, participating children accounted for 29 inpatient admission episodes to hospital. The breakdown and nature of these episodes are outlined in Table 2. Out of 29 of inpatient admissions, 12 were initiated by the remote consultation episode (41%), with the commonest reason being related to abnormally low oxygen saturations (five out of 12 admissions; 42%). These encounters were of particular importance as on two occasions this led directly to a cardiac catheter intervention for these patients. Out of 27 patients, five (18%) had either a catheter or surgical interstage intervention during the study period. The total number of inpatient days recorded as a result of a remote consultation for this cohort was 44 days. This figure represented approximately 30% of the total number of inpatient days accrued by the study population over the recording period.

During the study period, a total of 38 attendances/admissions to hospital were avoided as a direct result of the remote consultation. The breakdowns of the overarching reasons for these episodes are outlined in Table 2. The commonest reasons for this included medication and feeding advice (both 42%).

Table 1. Summary of complex CHD diagnoses amongst study population

| Primary cardiac diagnosis | No of cases |
|--|-------------|
| Tetralogy of Fallot | 8 (25%) |
| Atrioventricular septal defect | 5 (16%) |
| Ventricular septal defect | 4 (13%) |
| Shone's complex | 3 (9%) |
| Dysplastic tricuspid valve | 2 (6%) |
| Coarctation of aorta | 2 (6%) |
| Complex single ventricle pathology | 2 (6%) |
| Pulmonary atresia with ventricular septal defect | 1 (3%) |
| Transposition of the great arteries | 1 (3%) |
| Patent ductus arteriosus | 1 (3%) |
| Total anomalous pulmonary venous drainage | 1 (3%) |
| Cardiomyopathy with severe outflow obstruction | 1 (3%) |
| Restrictive and hypertrophic cardiomyopathy | 1 (3%) |

Nurse-led calls accounted for 48% of the total, with the remainder conducted by either the doctor with/without nursing support. The same doctor and nurse carried out all 201 remote consultations during the study period.

Secondary outcome measures

Participants' mean state anxiety was reduced from 34.9 to 34.2 ($n = 29$). Participants' mean trait anxiety was reduced from 32.2 to 31.4 ($n = 18$). Average State-Trait Anxiety Inventory scores for working adult females is 35.2 ± 10.61 ; average score for working males is 35.72 ± 10.4 ; both scores are age dependent.⁸ Although the numbers are small, there is no significant impact of timing of diagnosis on State-Trait Anxiety Inventory.

Over 95% of polled parents (using a 5-point Likert scale) agreed that Pexip was beneficial to both them and their child and that having Pexip available made it easier for them to manage their child's care at home. Parental feedback was extremely encouraging. Along with obvious medical benefits, there were accompanying psychosocial benefits to the remote consultation technology. One family commented "my husband is self-employed; when he's off, we are not earning." The financial burden of travelling to hospital can be significant for families with ill children. Additionally, the ability to have visual contact with these children was also well appreciated. Parental comments included "when leaving the hospital with my baby we were a little anxious at first, but the video call gave me great peace of mind. Especially because most of his symptoms are visual and hard to explain over a telephone call."

There were a number of minor challenges regarding the remote consultation interface and app usage. These were mainly some issues with poor/low audio levels and slow/low-quality video feed. These issues were often resolved with a simple reboot of the app and redialling the call. From the feedback questionnaires, a high percentage of the parents found the app easy to use (91%) and useful regarding their child's care (95%).

Discussion

During the COVID-19 pandemic, this study was designed to allow remote consultations as an alternative means (to face-to-face

contact) of maintaining ongoing surveillance of this vulnerable patient group.

The concept of remote patient monitoring and telemedicine began within the United Kingdom around 1991.¹³ Limitations at the time of its inception included the technology itself, financial constraints, and generalised resistance to change along with limited internet bandwidth.¹³ Its use since then has continued to grow and evolve as technology has advanced and into the internet modern area with most mobile phones now carrying the ability to deliver high-quality video and still images at the touch of a button.

Since the emergence of COVID-19, the uptake and use of remote consultations to supplement patient care has increased.¹⁴ Both the British Medical Association and Royal College of Physicians actively encouraged clinicians to participate in remote consultations where possible, during the pandemic^{15,16}. Hospitals across the world began to augment their use of remote consultations,¹⁷ including some in the United States which shifted elective ambulatory units to use this type of technology.¹⁸

The advantages of remote consultations have been well documented. This technique has been shown to reduce admissions to hospital¹⁹ whilst safely maintaining social distancing procedures²⁰ which were in force during the height of the pandemic. The technology available allowed for a communication method which was convenient and had potential cost-saving benefit to parents.²¹

Access to healthcare was significantly affected during the COVID-19 pandemic. Prior to COVID-19, the Royal Belfast Hospital for Sick Children paediatric cardiology department conducted up to 100 outpatient appointments per week. It was therefore necessary to find alternative means to engage with these patients without significantly compromising the care they received. During the pandemic, there was also a marked deficit in patient access to primary healthcare. This highlighted the extreme importance of remote consultation research for this patient group.

The use of remote consultations allows wider access to health professionals for patients and parents. This can result in a reduction in costs incurred by both the parent(s) and the healthcare service.²² It was important for this study to comprehend how remote consultations could be best used to monitor paediatric cardiac patients at home. This includes potential disadvantages to its use, along with comparing the technology to conventional face-to-face appointments.

The use of the remote consultation service had previously been established in the Northern Ireland tertiary paediatric cardiology unit. The type of technology used has progressed since its introduction over the past 15 years. The system had previously utilised Tandberg monitors which were fixed in one position within the family home and required professional installation along with a dedicated Integrated Service Digital Network line connection. Currently, the department uses the Pexip interface. This is a fully General Data Protection Regulation-compliant programme with an accompanying secure mobile application. A secure consultation is important where matters of patient confidentiality are concerned and this is often shared by users in similar studies.²³ The app is able to be used on any mobile device and has an easy-to-use interface which was well received amongst the study population.

Other clinical specialties outside of paediatric cardiology have demonstrated the usefulness of remote consultations. A team based at Spaulding Rehabilitation Hospital in the United States surveyed 205 of their patients and received high patient/parent satisfaction ratings of 93.7–99%, including the technique being well accepted amongst their paediatric cohort.²⁴

Table 2. Summary of hospital admissions initiated by and negated by remote consultation (RC)

| Inpatient episodes during study period | | |
|--|-------------------------------|--------------------------------|
| Total active study population | <i>n</i> = 27 | |
| Total inpatient admission episodes | <i>n</i> = 29 | |
| Total number of inpatient days | <i>n</i> = 148 days | |
| Individual number of patients admitted | <i>n</i> = 17 | 63% of total participants |
| Reasons for admission | Number of admissions | % of total admissions |
| RC related (8 patients) | <i>n</i> = 12 | 41% |
| • Low saturations (2 patients) | <i>n</i> = 5 | |
| • Suspected infection (3 patients) | <i>n</i> = 3 | |
| • Feeding related (2 patients) | <i>n</i> = 2 | |
| • Increased heart failure symptoms (1 patient) | <i>n</i> = 1 | |
| • Commence new medication (1 patient) | <i>n</i> = 1 | 34% |
| • Post-operation/intervention (10 patients) | <i>n</i> = 10 | |
| • Other acute presentation (5 patients) | <i>n</i> = 7 | 24% |
| Attendances to hospital avoided via RC | | |
| Total hospital attendances avoided | <i>n</i> = 38 | |
| Number of individual patients involved | <i>n</i> = 17 | 63% of total participants |
| | Number of attendances avoided | % of total attendances avoided |
| • Feeding related | <i>n</i> = 16 | 42% |
| • Medication related | <i>n</i> = 16 | 42% |
| • Wound related | <i>n</i> = 3 | 8% |
| • Breathing related | <i>n</i> = 1 | 2.5% |
| • Rash | <i>n</i> = 1 | 2.5% |
| • Social concerns | <i>n</i> = 1 | 2.5% |

The design of this project was not to replace face-to-face consultations, rather to supplement it and optimise patient care during challenging times. A continuity of care was maintained by the fact it would only ever be the same two health professionals carrying out the consultations either together or separately.

The previous model of remote consultation with paediatric cardiology patients had been more bespoke with a smaller patient size. Since the timeframe of the effect of COVID-19 upon the health service's ability to conduct face-to-face consultations was not yet fully known, it was pertinent to research and develop a model of remote consultation which would expand the existing service. Moreover, at a time when access to primary and secondary healthcare was reduced, the need for parents to have access to specialist clinical teams regarding their child's healthcare became increasingly important.²⁵

The effects of COVID-19 are likely to provide ongoing challenges to healthcare provision beyond this acute phase. Even though the expansion of companies providing remote consultation platforms has been increasing since 2018,²⁶ more work and infrastructure changes may be needed. The aim of this would be to make up for the deficit in patient care as a result of COVID-19 and to be able to implement remote consultations as a more permanent fixture in the patient review algorithm in hospitals worldwide.

Limitations

The overall patient sample size is small and remote consultations were only scheduled 1 day per week. The time from consent/discharge from hospital to first remote consultation was 23.6 days. This may be explained by the fact that a large number of these infants required regular face-to-face review involving advanced cardiac investigations such as echocardiography.

Although the feedback from parents strongly indicates parents favour Pexip, it was not demonstrated as clearly in the State-Trait Anxiety Inventory scores. Despite the State-Trait Anxiety Inventory scores showing a downward trend, it was perhaps not as impressive as anticipated. Research has demonstrated that parents of children with CHD display higher levels of stress compared with parents of healthy children.²⁷ This may help explain the observed results in the State-Trait Anxiety Inventory scores. The REmote Assertive Community HomeCare (REACH) protocol studied in 2018, examined the effect on parental stress levels, with a similar cohort of patients with complex CHD using a remote consultation service.²⁸ The study demonstrated the virtual visits were well received; however, the levels of parental anxiety were not significantly reduced. A potential reason for this may be that the remote consultation reduces the stress level during the remote consultation, but is unable to address any ongoing or chronic stress to the family or patient.

About 44% of parents received an antenatal diagnosis of their baby's CHD. This antenatal diagnosis would have been coupled with counselling and regular review with a fetal cardiologist prior to delivery of their baby. Moreover, at the mean age of recruitment (9.3 weeks), in all likelihood the families recruited would have numerous discussions and interactions with medical, nursing, and allied health professional staff within the paediatric cardiology team. This may have culminated in a reduced baseline anxiety State-Trait Anxiety Inventory score. Further research may attempt to measure State-Trait Anxiety Inventory scores at the initial time of diagnosis. A further detailed analysis of the State-Trait Anxiety Inventory score is the subject of a second paper from a member of the project team.

Unexpected issues about maintaining breastfeeding in very unwell infants arose during the study and demonstrated a need for specialist input and targeted resources that are evidence-informed and clinically viable. Infant feeding is a known area of concern and of immense importance to both infant and maternal health and well-being. During the COVID-19 pandemic with government restrictions, research has shown that mothers felt less supported by community groups such as breastfeeding support and other child health services.²⁹ However, based on the findings from this study, we have identified it as an area for further multidisciplinary research.

Conclusions

The remote consultations allowed important medical interventions to be made remotely as well as reducing potential attendances to hospital during a time where face-to-face consultations were significantly reduced. Pexip remote consultation technology was widely accepted amongst the recruited families. Over 95% of polled parents agree that Pexip was beneficial to both them and their child and that having Pexip available made it easier for them to manage their child's care at home. The study was able to maximise medical impact during very challenging circumstances. Children who required admission to hospital were identified and treated, whilst those who do not were protected from attending hospital unnecessarily, all without compromising their clinical care.

Key learning points

1. Remote consultation during COVID-19 pandemic was a very important adjunct to care of children with CHD.
2. High level of parent acceptability and positive response to the programme.
3. User-friendly technology is crucial.
4. Early identification of clinical deterioration facilitated by regular remote consultation.

The study has demonstrated the role of remote consultations using up-to-date user-friendly technology can be used to improve care of vulnerable patients including early detection of clinical deterioration when access in circumstances where face-to-face contact is challenging.

Remote consultations should be considered for integration into routine outpatient clinics as an additional option for patient review.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951124026295>.

Acknowledgements. The authors wish to thank the participating families along with the Children's Heartbeat Trust and Ulster University.

Financial support. Ulster University and the Children's Heartbeat Trust funded this project.

Competing interests. None.

Ethical standards. Ethical approval was sought in May 2020 and obtained by October 2020. Ethical approval was granted by the Cambridge South Research Ethics Committee and Research Governance approval by the Belfast Health and Social Care Trust Research Governance Department on 6 October 2020.

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Appendix 1: Equipment

Masimo Oxygen saturation monitors. Masimo Rad-G Pulse Oximeter. <https://www.masimo.co.uk/products/continuous/rad-g/>
 Weight scales: Seca 384 weight scales. https://www.seca.com/en_mt/products/all-products/product-details/seca384.html#referred